

**Introductory note by Lise Menn****SHIRLEY SAYS: LIVING WITH  
APHASIA**

**- Notes for people with aphasia and their families.**

**by Shirley Kleinman with Lise Menn, Ph.D.**

Shirley is my friend, and she has aphasia - that is, she has problems with language because of a stroke (other kinds of brain damage can cause aphasia, too). She had the stroke twelve years ago, when she was 63, and at first she couldn't talk at all. She still has problems speaking and walking, and her right arm is useless, but she's a really fine communicator, and what's more, she has a lot to say about how to get the most out of life after a stroke. She's an expert on living your life as fully as you can, no matter what. She's also really good at explaining the everyday problems and annoyances that are so discouraging for aphasic people, so that families and friends can understand them and be more helpful.

Here in Colorado, Shirley is often invited to 'be the aphasic' at U. of Colorado Medical School lectures or at the CU Boulder Speech Clinic programs for students and for aphasic clients and their families, because she has learned to be such a powerful communicator. She insists on - and gets - respect from

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physicians, clinicians, and students. Last year, she told me about the kinds of advice she'd been giving at a Speech Clinic panel, and I said I thought she should write a booklet, so that more people could benefit from her ideas. I promised her that if she wanted to write one, I'd help her get her words into the kind of English she would have been able to write before her stroke.

In what you read here, the ideas are all Shirley's, and all the experiences she describes are really hers. She dictated these stories and reflections to me, using all her resources of words, facial expressions, tone of voice, and gestures. I paraphrased what she said in regular English, and gave it to her to read; then we revised it together until I got her story right. Sometime she wrote a word instead of saying it; those words are in CAPITAL LETTERS LIKE THIS.

And some of the words, the ones in *italic letters like this*, are exactly Shirley's own spoken words. So if the aphasic person you know has the same kind of aphasia (moderate Broca's aphasia, also called expressive aphasia

or agrammatic aphasia), you'll be able to recognize the kind of language she uses now.

But even if you, your friend, or your family member has a different kind of aphasia and speaks very differently from this or not at all, a lot of what Shirley has to say may be just what you needed to hear.

- LM

\* \* \* **SHIRLEY SAYS** \* \* \*

### About this book

I will say right now, when you talked about us writing this book, I thought, *When you write: who will read?* But now I think people will be able to recognize some of the experiences in it, and will come to understand more about what life with aphasia is like.

Still, everyone's experience is different.

### Kinds of aphasia

One thing that we have to make clear at the beginning is that there are many different kinds of aphasia. Lots of people have heard only one kind, the kind that they or their friend or family member happens to have. I didn't really understand this until I was on a panel of people with aphasia at the University Speech Clinic. Only one of the others sounded like me.

### Everyday annoyances

#### Ignorant people

One day, a week ago, I answered the phone. When I said hello, he says,

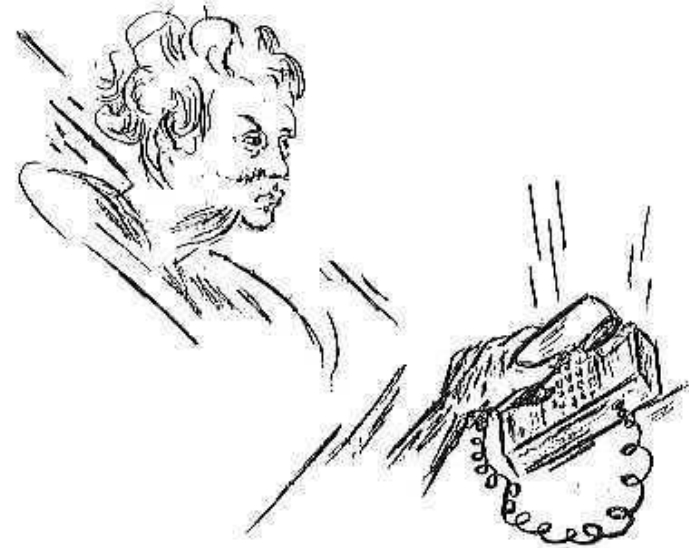
'Where's your mother?'

That's happened several times in the 12 years since I had my stroke.

I am me, but what somebody hears is something different. I thought I'd been making progress in my speech, so something like that is discouraging.

Because I'm feisty, I said, *My mamma busy.* Then I hung up.

All of a sudden, like half an hour later, he called again; the same thing happened.



So I told him, *My momma said: Don't bother.*

But it's hard for me to put up with things like that. If I could see the person, I'd scold him.

### **Laughing and crying**

For about the first four years after my stroke, I would start to laugh about something funny and then the laughing would change to crying. But I wouldn't feel sad. It was just that *my brain don't know what to do. Change - today, I laugh and no cry.*

### **What will people think?**

I miss being able to salute when I hear the national anthem - I can stand up, but I'd have to use my left hand to pull my right hand over my heart, and it's really too stiff to keep it there.

And also I can't sing the words; so I worry that maybe people around me think the worse of me because I'm not singing. It doesn't keep me from going to a game, though.

When I went to a restaurant, just after my stroke, I felt that people were looking at me with pity. But I decided that I will stand up straight, and not look for sympathy.

When my husband Abe and I went to restaurants, I felt he was too protective at first. I wanted to be as independent as possible. But then, people don't know my attitude. Maybe if he didn't help me, people would think that my husband wasn't looking after me properly?

I had altogether too much time to brood about things like that...

### **Frustrations**

I listen to people more because I can't talk; that's not bad, I guess. But - I wish I could give advice.

I heard somebody talking about wisdom and philosophy on TV. I wish I could talk. To some people, I want to say, "Don't be judgmental, consider other points of view..." and to others, "Well, you're so full of political opinions - did you go and vote?"

*When I have my stroke, Sam was three. I cry because I can't read to Sam. That hard, real hard. I still - I can't read to kids.*

But before I had my stroke, I used to visit Ellen and Bruce and the kids every three months. I

used to help the older ones, Adam and Sheri, with their homework.

### **Being in groups of people**

When there are too many people, like at a big family get-together, sometimes I used to just want to hide in my room. It's too hard to understand what anyone is saying; I get frustrated and exhausted. Hard-of-hearing people have that problem, too, but I can hear okay.

### **Some things that have probably helped me**

A long time ago, I was a mimic, and I still am - when I went to the panel, or go to other places where I met other aphasics, I'd imitate them after I got home, so people would know who I'd seen. I was a real good mimic, a long time ago. When I was a girl, we lived over my father's little store. Once, when I was in the house, my father came upstairs, and I spoke to him, but I put on the accent of one of his customers, Rose, who was Russian. My mother, who was in the kitchen, heard me talking to him, and she called out, "Rose, how are you?" - but it was me!

So when I had my stroke, I think I was lucky because I can imitate, and I can communicate that way.

And I love to laugh. I wasn't serious very often; that may have been a good thing.

### **Volunteer work - being useful in your community, aphasic or not!**

You can work or volunteer even when you are aphasic, but almost nobody knows that. I was lucky; someone my daughter Ellen knew suggested that I could help at elder day care. *You know, I'm really feisty.* I went to Longmont every Wednesday, and I worked in the elder day care, walking with women to the rest room and back, and turning on the TV for people - and I can hardly speak! Because twelve years ago, it was different. I couldn't speak as well as I can now.

Then I went to the Boulder volunteer services office and said, *I can file*. But at that time, I still had trouble remembering the alphabet, ABCD... so I copied it out of the dictionary, and kept the slip in my pocket. I worked in the library at the elementary school.



*School library, yes, you don't have to walk, you don't have to talk, you sit right here and file, little card.*

My speech teacher, Clara Wachtell, encouraged me, too. One day, when Clara and I were talking, I said to her that after my stroke, I had volunteered in the court house at the driver's license bureau, and I knew how to file. She said I should volunteer right there at the hospital. So that's where I work now, in the medical records office.

### **Coping with not being able to say words**

I went to the university Speech Clinic, and I saw other people who have aphasia. Some of them were using writing to help communicate, like I do, but they abbreviate a lot, just writing the beginning of a word. For me, the word seems to evaporate in the middle sometimes, and I guess it's that way for the other people too. I see the word I want in my mind at first, but then as I write, I can't remember how it goes. But what gets on the paper is usually enough for others to guess what I mean, if we've been having a conversation.

A line about laryngitis I heard: "The trouble with laryngitis is that you have to wait until you are cured to tell anybody about it." That's like aphasia.

## Feelings

### Guilt feelings

Two or three years after I had my stroke, I went to a psychologist because I felt guilty. After all, my poor husband - he'd never cooked or done the laundry and now he had to do it. And he'd only retired a year before my stroke; we had planned to do all sorts of things, especially traveling, when we retired, and now we couldn't do them, because of me. The doctor said I shouldn't feel guilty, but I did. It took me one whole year to say, *I not guilty*.

The family has to know that the person is not guilty - but they also have to know that everything has changed.

### Being different, and feeling that other people are different, too

I remember my daughter Ellen trying to explain about me to her son Sam when he was little. Sam was asking her, 'What happened to grandma?' But Sam's question wasn't about my stroke, about my arm or my speech. It was about why I wasn't rushing around, getting all sorts of things done, then rushing back to New

York again. When I helped his older brother and sister with their homework, I had been very demanding. My style was: *Hey! Think about it!* Ellen said, 'Grandma's thinking on a HIGHER PLANE now.'

Later, Ellen and I talked, and she said, 'Mamma, you're nicer now.' *I'm different, because my brain different.* I've had a personality change, I'm not so much of a perfectionist, not so hard-driving.

The first three days after my stroke, I had no speech at all, and no memory, I was amnesic. And it was hard when I went home. I recognized my husband, but he seemed different to me in some way.

### Family support

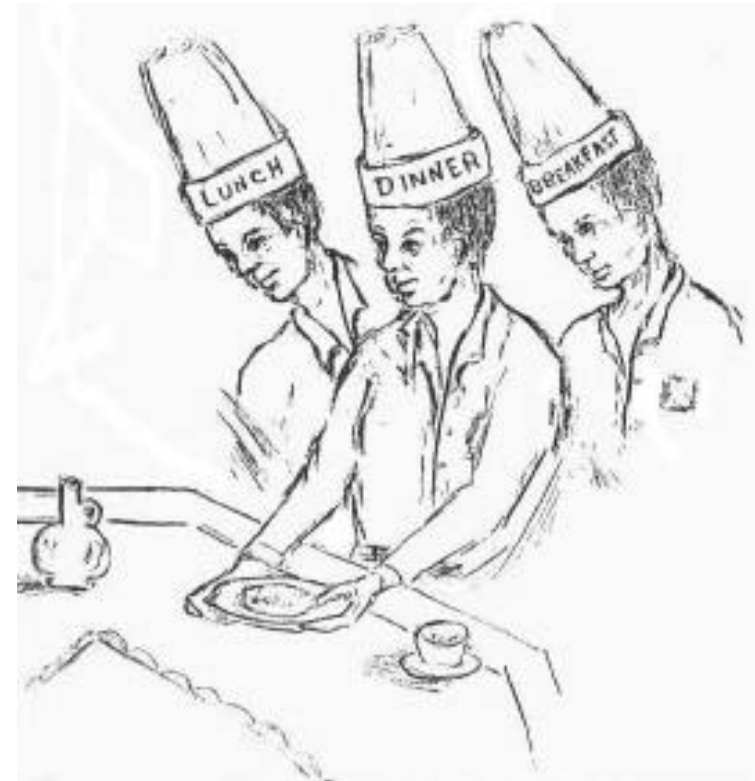
I feel, *God shone on me.* Look at the circle of support that I have! My two daughters, Ellen is a teacher for the deaf, and Sandy was trained as a speech pathologist and now she's a neuropsychologist. I'm very lucky. *Because the first day (after I got out of intensive care), and Sandy right here. Sandy, talk all day. Mamma, you can speak. Not right now, but you can. First day, you will [have] somebody to teach you how to talk.*

Sandy insisted that I start speech therapy right after my stroke. Doctor said 'later', but Sandy said 'right now.' Not later, but now, right now. My first speech teacher was Lisa \*\*, and I love her very much.

We learned that people with families have the best chance of recovering language. That was the main reason we decided to move out here where we have Ellen and Bruce and the grandchildren.

When we moved to Boulder, thank God, my daughter and son-in-law and grandchildren were here to treat me as grandmother and look after me. And Ellen called around and found more people to help me.

And Ellen write down you go to store and buy, what, and stove, you know, all that. Ellen taught Abe how to shop and cook.



I depend on Abe for meals; Abe depends on me for memory. I'm 75, but Abe's 79.

### **Patience**

My husband Abe knows that I frustrated [when I can't find a word that I want but ...] y'know, my friends, [if they can't help me find



my word, they say], "later". But Abe knows that inside that I have - he knows how hard for me to say - right now, I have to [find that] one word - see, Abe knows, that I have to know now. So he keeps on thinking about what my word is, he'll work on it for five minutes if he has to, until he can find my word. That's love. My teacher - one hour, go home; he [Abe] was teacher in the house!

The fact that I can do something, I think it's because I read, I watch CNN, I keep learning.

Then sometimes I fall back...Sometimes, nobody talks to me.

### **Missing the stories when people talk fast**

When I'm at work and other people start talking about something interesting, they usually speed up so much that I can't understand it all, and then if it was funny and they start to laugh, I'll really feel left out. But my office-mates and my friends, they know that; every few minutes, someone will say: did you get that? and if I didn't, they'll tell me again, more slowly. That's a big help.

### **Learning from TV**

Before my stroke, I used to watch Jeopardy, but after the stroke, I couldn't read the words on the screen. I cry, said every day, I have to, I have to. Five days a week. I learn - that hard, real hard. Not one month. Years. Wheel of Fortune [is] different, I have to ABC, have to think about. Maybe 3 years, then I can real good, you know. Phrase, person. Thing. Phrase is hard, real hard. The phrase, still hard. I think watching those programs helped me.

### **Being afraid**

I used to be afraid to be alone when Abe went out to Kiwanis meetings. I would imagine what might happen - if there was a fire and I couldn't get out, what then? So my grandkids, Sheri or Adam, usually came to babysit.

One day, Abe went to Kiwanis. I have stay home. Alone. I saw the doorknob turn. I was really scared, but I thought, if I call 911, who would understand me? So I called Ellen. But she was out, and Adam answered. I said *Somebody like - the door - I 'fraid!* You know, he got a baseball bat and got on his bike and

started to ride over here! But in fact, it wasn't a prowler that turned the doorknob - it was just two girls who were looking for a lost cat.

### **Getting past 'being the patient'**

After my stroke, everybody took care of me. Then I went home, and I thought - somebody take - of me , same thing. I was SELF CENTERED.

Then, about 5 or 6 years ago, I suddenly realized how I had been acting. I say to Clara: ... I never say 'Abe, you're hurt?' For years, I had forgotten to think about other poeple's feelings, their point of view.

It is hard for the family, to have an aphasic person to take care of.

After my stroke, I think inside, it's lonely. I thought at first that I was the only lonely person. But now I know, inside, everybody have little loneliness. Only before my stroke, I was too busy to notice. Now, when I have my stroke, I think about life. I finally had time to get philosophical, like my father and brother Leon.

### **Being able to answer**

One day Gail called, and asked if I needed someone to take me to the store. *I like that.* But what Sara did that was even more important was to help me to say one word - Connecticut. She showed me how to break it up into smaller pieces - *Connet - cut.* Because that's where I grew up. When I couldn't say it, it made me feel backward, because when you meet people, they ask 'Where were you from? Where was your family from?'

You have to talk, to be able to take your turn. Before I learned to say it again, I used to write it. At least that was something.

My younger daughter, Sandy, said. *Mamma, you have to write. I thought, left hand...* And it took me a long time to learn to write with my left hand like I do now. When I was in the hospital, Sandy kept a daily notebook of what happened. You can see how bad my writing was then.

Place for a copy of Shirley's June 1985 attempts to write

## Learning to say some important words

For a long time after my stroke, *I can't say the holiday, but now - I say - sank you, like that, Sank-giving.*

And Clara had other ideas. The word "How" - *I can't hear (inside my head).* So I couldn't ask that kind of question. Clara said to think of the puppet Howdy Doody. That helps me get started right, so now I can say *How you do that?*



## Word lists

I have a notebook. At first, Ellen and other people would write phrases in it for me, things I really used to say.

That's right

You never know

That's enough

Later!

So what, who cares.

Now, sometimes I read a word or a phrase and I think, *That me.* Or maybe I hear it on TV. So I copy it in my book. Then I can find it. Here are some of my words and phrases.

Kids today are so crazy.

Belligerent

Agitated

Defiant

Frustrated

Put a cork in it

Stick it in your sassafras

Don't have a meltdown

Chill out, dudes

Spit it out

Have a good life  
 My heart is filled with joy  
 (that's from a card)

I need some reassurance  
 I haven't time for nonsense  
 Don't annoy me  
 Take good care of yourself

Here's something Sandy told me I should say:

Don't be afraid of me.

That one helps.

I carry a card, too. Here is what it says:

When you don't understand me,  
 please let me know. Tell me. I will  
 say it for you again.

And three years after my stroke, a friend  
 wrote this for me , to show to people:

I have problems understanding.  
 Please speak slowly and look toward me.  
 My brain is good and I want to understand  
 what you say. I have an inquiring mind and  
 want information from you.

### **Understanding what you see at the stroke club**

Lots of people will tell you, 'go to the stroke club'. Yes, you can learn a lot and find support there. But you can also get very confused and upset, if you and your family don't get enough advice from your speech pathologist, because there are so many different ways that strokes can affect people.

Some people are paralyzed on one side, some are not. Some who were partly paralyzed recover better than others. Some people seem to talk just like normal, some seem to talk too much. Some, like me, have a hard time talking. How can you know who you are going to be like? How can you know what it's realistic to work on?

You can't, by yourself. So talk to your speech pathologist, ask questions when you are puzzled by what you see.

### **More about kids**

*Kids - real good for people who brain injury - real good, kids. Because they laugh, **but not in a way that would INTIMIDATE me.** Because [they are] my family, [not] outside people.*

*Little kids don't have much language. So when I talk, [it's] like kids, four, three, same thing. But I can't understand kids. [Not until] after kindergarten.*

**When they see my cane, sometimes kids say 'What that?' And I said, 'Oh, I can't walk. But the doctor said, Later I will walk.' Then, you see the kids, 'Oh'. Okay. They can deal with it if I explain it that way.**



*Because if I said (sad face), 'I can't walk ...'*

**No! That wouldn't do; that would upset them.**

## Respect

Aphasic people need RESPECT. My family was real respectful. But I've seen families where the aphasic person was treated as if they had no understanding. *'You don't know, you don't have a brain.'*

Once in the hospital waiting room, I saw an aphasic woman's grandchildren treating her like *'You don't know what to do'. I thought, Oh, God!* Their mother didn't stop them from acting that way. I don't know, maybe the mother didn't treat the grandmother with any respect, either.

## Other things people have written out for me

Written in 1991, by a friend taking dictation from Shirley:

Then I met a special angel in the hospital, Clara Wachtel, who taught me how to never give up and my world is different. I like my life. (Now - 1997 - , I love my life.) Sometimes when I think about the hospital, I think "hope". Everyday I hope. I think the name should be "Hope", not Mapleton.

## Writing checks by myself

It's hard to feel independent when you can't write a check. The other person could fill in

their name, but I wouldn't want them to put in the amount! After I could write the numbers well enough, I still had trouble with writing out the amount in words. So Clara wrote out a list of the number words on a page at the front of my checkbook: One, two, three, four... and then I could go shopping. Of course, most places you can use a credit card - but not everywhere!

## Meeting a challenge

Susie HANSEN, my boss, and she told me - Sue ..one day Sue said to me, I like the think about, how 'bout you like the computer. So I said I never thought - Clara, one day, yes, she one day said 'Maybe you like the computer', but I said no. [With] that computer, you have to type. But I like to [write]. [With a computer], you have to think about the ABCD here - my brain don't know what to do. So back to Sue: say: 'Shirley, try'. [Well, this time, it was] my boss [talking. So I] said: 'Yes.' But Sue have patience, oh! - and she taught me how to use the computer for medical records.

*I love her.*

### What it's like, being aphasic

*Jail and I can't open door. I can't explain, ...  
I see [through it], I think I can [get out, but I can't,  
it's] like a plastic door, my brain, jail. That's why  
'frustrated', 'belligerent'.*



Or, when I read, then I have to say *wait a minute*,  
It's like being tangled up in YARN , and trying to  
get untangled from it.

End note: Shirley's speech, reading, writing, and  
communication are still improving, year by year.  
They will not become perfect, but they will keep  
getting better. Being realistic does not mean to  
stop trying. Don't give up! - LM

This booklet was created with the help of the Computer Laboratory for Instruction in Psychological Research and the Institute of Cognitive Science at the University of Colorado, Boulder. Thanks to Prof. Gail Ramsberger and the Speech Clinic of the University of Colorado Department of Speech, Language, and Hearing Sciences for help and support.

You are welcome to print out this booklet for distribution to anyone that you think would be helped by reading it.

Comments may be sent to [lise.menn@colorado.edu](mailto:lise.menn@colorado.edu).

About the authors: Shirley Kleinman became aphasic in 1985. For 35 years before that, she and her husband ran a small business together. Lise Menn is a linguist specializing in aphasia research and psycholinguistics; she was trained under Harold Goodglass at the Boston Veterans Administration Medical Center, and now is a linguistics professor at the University of Colorado, Boulder. Shirley and Lise became friends after Lise started studying Shirley's speech for a research project in 1988. Abe Kleinman died in 1999, at the age of 81; now Shirley and her family are facing a new round of problems and decisions.

If you maintain a website for people with aphasia and their families, for speech-language pathologists, for other providers of services for people with aphasia, or for students of language disorders, we encourage you to construct a link between your site and this URL.